

## Kawhia Cruise 2014

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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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ManuScript is brought to you by:



Sir John Logan Campbell  
Residuary Estate



Bad news / good news. I was looking forward to the Cruise after enjoying last year's event and meeting some really cool people (not to mention giving some bikies the evil eye and getting away with it). But on the morning of the Cruise the ole body didn't exactly play ball and I had to wave the white flag and give the event a miss. The good news is the event went ahead, was a success and ... because I wasn't there you get a report based purely on facts and no waffle!

I'm sure it was purely coincidental that I wasn't there and heaps more people turned up! About 100 cars made it to the Jukebox Diner - starting venue for the rally. Even Adam was slightly taken aback - "I didn't know half of the people - they were popping up from everywhere - it was great". The difference between this year and last year was the fact there was a 'last year'. Word of mouth, name recognition, more information and activity on face book and interest generated from newspaper articles combined to boost this year's attendance. One of Adam's aims for holding the Cruise was to raise awareness of MS. This he has achieved handsomely. On a personal level - I have had people approaching me inquiring whether I know that dude



in the paper doing that cruise thing for MS. Of course, I assured them that it was all my idea and pocketed any donations offered ... - just joking Janet! Another key difference from last year was that Adam had help - friends Ray and Joanne Young assisting with organising the event and the car club he belongs to 'American Muscle Cars' stepping up their involvement.







Anyway my sources tell me it was great family atmosphere at the Diner where shirts, caps and other paraphernalia were sold and the free balloons went down a treat. After a grotty weather forecast it was fine

castle. The 'Pav' man was back again to auction off some more stuff to eager bidders. There was a special moment when two model cars (Adam had brought back from the States) were auctioned off. Half way through the bidding for the 'Dodge Super Bee' Adam decided he wanted to keep it and starting bidding. *"This young fella out bid me and I was a bit disappointed – but he turns around and gives it to me. I have never seen him before and he does that – nice bloke"*.

and sunny as the cars eased their way out of the car park on the first leg of the journey to Pirongia. Adam led them out driving a 1958 Apache Chevrolet on its first road trip. *"Yeah – it had only been ready for a day or day or two"* says Adam. He bought it for wife Shelley but it arrived from Sacramento in March – a couple of days after Shelley died from cancer. *"It was really important to me that it made this trip – it meant Shelley was with me – it represented us"*. Shelley's other car – the beautiful orange and white 1955 Chevrolet I went in last year was driven by Shelley's parents.

The promised rain started to drizzle as the cars left Oparau for Kawhia and a few of the cars decided to head home. But about 100 cars rolled into Kawhia parking up around the Kawhia Green, the drizzle turned to bright sunshine, prizes were given out and the crowd was entertained by the band 'Shotgun' who kept everybody in a happy mood with some classic songs of days gone by.

Stopping in Pirongia gave the stragglers a chance to catch up. When all the cars caught up they were quite a sight lined up on both sides of the street for several hundred meters. Locals were seen scribbling letters to the local council suggesting traffic lights and pedestrian crossings be installed before next year's event.

Adam tells me he left Kawhia about 5.00pm so it was good day out. He lists his highlight as watching all the cars pulling into Oparau. *"It was just great seeing all those people I didn't know. It's gaining a momentum all of its own"*.

On to Oparau where the 'cruisers' stopped for a coffee and a chinwag while the kids played on the bouncy

All in all the 'Cruise' bought in \$4,315 plus good publicity. Good to see Graham (boss of the BOT), Liz and Tracey on this year's event. Will it be on next year? Yep, 1 November 2015 – see you there.

**Ian Maxwell**

Kawhia Cruise T-shirts are still available for purchase from the MS Waikato office for \$25 each.



## Bye Helen



At the end of this year our hard working ME/CFS Client Services Coordinator, Helen Maseyk will be leaving us. *"I've decided it's time to retire and spend some quality time with my husband. I'd like to travel, catch up with grandchildren ... and I might even get a bike."*

Helen, a registered nurse, joined MS Waikato in March 2009 after spending some time working at a head injury rehab unit. Helen was brought in to carry on the great work initiated by Frankie Letford who had championed the case for ME/CFS and FM patients to be brought into the fold and have support services provided under the MS Trust umbrella. Helen was initially responsible for around 100 clients, this has grown to almost 200 clients situated in an area ranging from the Bombay hills in the north to Taumaranui and the Coromandel.

When she started Helen didn't know a lot about ME/CFS but has learnt a lot along the way. *"This is a very*

*complicated and complex illness."* For clients it is often a struggle to get diagnosed. *"Many GP's know very little or nothing at all about the condition. Part of my job was to raise awareness of the illness in the medical community and help to educate them, as well as the general public."* Helen produced a newsletter 'Koru' which was sent to clients and those associated. She also organised monthly support group meetings where speakers were brought in to discuss their areas of expertise which may have been of benefit to the members.

When prospective new clients contacted Helen she was able to point them in the right direction and help them with advice and a management plan. *"It was always very satisfying to meet new people and set them on the road to diagnosis and then management of their illness. ME/CFS is a very misunderstood illness and many of my clients struggle with the lack of understanding shown by others."*

When I pressed Helen to name a highlight of her time with the MS Trust she simply said that this had been the most satisfying job she had had in her entire career in health. *"Virtually everything I had learned over my career I had to call upon to carry out this role. It was challenging at times but I have really enjoyed working with the clients and the MS Waikato team."*

**Ian Maxwell**

## ME/CFS Update

Nearing the end of the year is always a good time to reflect, and although it seems to have rushed by, it has been a very productive year. Our numbers are up, which means more people are receiving support, and judging by our referrals, more health professionals and people in the community are aware of the ME and FM support we provide.

We have had some excellent speakers at our Support Group. The last two meetings included a very informative talk on Tinnitus and Hyperacusis (noise sensitivity), by Hearing Therapist, Cherry McWha, and Tracey Larsen facilitated an excellent interactive group discussion on 'Relationships' last month.

Tracey and I were privileged to assist renowned Melbourne paediatrician, Dr Kathy Rowe, recently when she gave a lecture on the management of children and adolescents with ME/CFS to medical staff at Waikato Hospital.

We will be winding up with our Christmas lunch on 11th December, and I too will be 'winding up' shortly afterwards, leaving things in Tracey's capable hands.

Thanks to the great team at MS Waikato – it has been a pleasure working with you.

**Helen Maseyk**  
**Client Services Coordinator ME/CFS**





## Exercise Class

A big thank you to Denise Erb (centre front), who stepped in to look after us lot at the gym while Margaret went back to Scotland! Denise was an inspiration to all of us and I'm sure we are all a little better off from our involvement with her. Denise's story is that she was a single mum of 5 children – unemployed and overweight. She decided to change her life and got a job cleaning at Anytime Fitness. While she was employed there she took the opportunity to use the facilities and started working out. She lost over 50kg and was so enthused by the fitness regime she put herself through a personal trainer course. She is now qualified and contracts to Anytime Fitness with her own client base. She doesn't preach but offers life style advice and an exercise programme. She gets great pleasure from watching her clients make the same transformation she did. Thanks a lot Denise!

Pictured with Denise and having our usual coffee are gym bunnies Louise, Brian, Stephen, Ian, Steve, Paul and Warren.

### *Ian Maxwell*



***Louise, Brian, Stephen, Denise, Ian, Steve, Paul and Warren***

## OPR4

Here I am at Chateau Rehab  
With its views out to the Lake,  
Where dinners brought right to me  
Plus the pills that I must take!

Outside my window is a tree  
With pale green leaves of spring,  
The grass is mowed, I can see the road  
And a glimpse of many-a-thing!

Fat pigeons fly away up high  
To land upon a ledge,  
But tiny swallows flit and dart about –  
Such grace with tails a-wedge.

Then came a busy (quizzly) bumble bee  
It bumbled by the glass,  
It means I'll have a visitor  
I wonder – will it come to pass?

And then there was a plastic bag  
Filled with breeze and slowly rising,  
It had escaped its earthly fate  
Forget that shopping – let's go flying!

But best of all across the road  
We watched a wondrous sight,  
A car did come, a nurse did run  
A babe was welcomed to the light.

And now the day is over –  
Darkness gathers all around,  
The lights are on now everywhere  
So I know that we'll be found.

Then come the night-time angels  
With wings upon their feet,  
They help us pass the night time hours  
And settle those who cannot sleep.

This place is such a haven  
To those that need some care,  
I feel privileged to be here  
My thanks and prayers I bear.

### ***Rosalind Dean***



## PHARMAC's announcement a positive step forward for the MS Community

The Multiple Sclerosis Society of New Zealand (MSNZ) is delighted by PHARMAC's announcement that it will fund two new treatments for Multiple Sclerosis.

After years of funding submissions, culminating in a campaign this year led by MSNZ, PHARMAC has approved funding for two new treatments and increased access to those currently funded for New Zealander's diagnosed with relapsing remitting forms of Multiple Sclerosis.

Biogen Idec's Natalizumab (trading as Tysabri) and Novartis' Fingolimod (Gilenya) will be funded from 1 November 2014. PHARMAC has also approved increased access to currently-funded treatments.

"This is a big step forward for people with Multiple Sclerosis in New Zealand," said MSNZ Vice President Neil Woodhams. "It means that many of those living with MS will no longer be subjected to a level of disability before their treatment is approved. This is a momentous day for thousands of people living with a potentially manageable form of MS and their families. The majority of these people are young women, many of whom are mothers. Earlier access to treatments has shown to greatly reduce relapse rates and halt disease progression.

"New Zealanders have waited eight years longer than Australians to be able to access these treatments. If we can act quickly to support people with MS so that they can access the best first-line treatments then they can remain in the workplace, manage their own lives and care for their families. MSNZ's campaign is based on an issue

of fairness and equality of access. Access to treatment wherever you are in New Zealand is a democratic right."

Strong concerns had been expressed to MSNZ that DHBs do not currently have the necessary access to resources to manage the changes these new treatments will bring about, says Woodhams. "Many of our DHBs are already understaffed. Canterbury DHB for example does not even have an in-hospital MS Nurse, despite having more than 400 people within its catchment area who are diagnosed with MS. "Nursing support is provided by our MS Society in the region, but this does come at a cost to the community and funding for these services is becoming increasingly hard to secure."

"We are glad to see that PHARMAC have heeded our concerns and has not ignored the importance of the current treatments remaining available for use, appreciating a person's individual clinical situation. This is particularly important for those out of the major cities where neurology services are limited. By also allowing general physicians to apply for MS treatments PHARMAC have taken a more person-centred approach making treatments more accessible and not restricted. "It has been heart-breaking to hear repeated stories of people having to become disabled before they are approved for treatment. Thankfully we are now heading in a more positive direction."

Press Release provided by the MS Society of New Zealand

## Pacing

At this busy time of year it can be easy to overdo things. Remember to pace yourself especially as the weather heats up and we head into summer.

Pacing involves taking planned breaks or rests within or between activities and can be equally important for either physical or mental activities. This can require a degree of self discipline as the natural inclination is often to try to get to the end of a task. However, it is often more beneficial to take things steadily rather than continuing with an activity to the point of exhaustion and being forced to rest.

Many people with MS find that if they overdo things their recovery time is much longer than in people who don't have MS. Where other people might recover their energy after a short rest, people with MS might find it takes them considerably longer.

Taking regular breaks or by doing tasks more slowly may help to stop fatigue from building up and avoid swings

in your energy levels. By doing this you may find you are able to achieve more than working straight through until fatigue becomes overpowering.

The heat of our summer sun can also affect some people with MS leaving you feeling fatigued too. This feeling can also be triggered by hot baths or showers, hot drinks or meals. These effects are usually quickly reversed when steps are taken to cool down.

Cooling techniques can be as simple as using fans, taking cool baths or showers, having regular cold drinks or sucking an ice cube. Neck coolers or cooling vests may also help to keep you cool. MS Waikato has one yellow neck cooler remaining for \$15.00.

Reference and for further information:

[www.mstrust.org.uk/information/publications/fatigue](http://www.mstrust.org.uk/information/publications/fatigue)



## HD Research

As promised in the last edition of Manuscript, other research studies discussed at the Huntington’s Conference in Perth in September will be shared over several newsletters. Today I share research regarding brain imaging -

Nellie Georgiou-Karistianis, a world leading cognitive neuroscientist, spoke of her research in IMAGE-HD, a world first multi-modal neuroimaging study. Imaging enables investigation of different tissue types and can note changes in structure, function, connectivity (between brain regions as well as individual parts such as neuron, axons and molecules) and weight, both in symptomatic and pre onset of symptoms HD participants. Structural imaging showed a change in molecule movement along the axon between neurons. Movement is usually uniformed like this ---- but in a HD brain it looks more jagged ~~~~ .

A change of the fibre connections between brain regions was also detected, indicating a breakdown of white matter which results in the disruption of motor circuits and poor cognitive performance. Once a resting state of the participant was established, a memory task was performed so that changes in the brain could be recorded. Results over 30 months



of testing showed a decrease in connectivity in pre-onset HD participants. Conclusions determined thus far shows that changes in the brain can be detected up to 15 years prior to cognitive, motor and psychiatric changes and onset of noticeable symptoms. Outcomes from this study will inform the design of future clinical trials.

**Tracey Larsen**

## Important Telephone Numbers

Your Own Doctor .....	Lifeline - Outside Hamilton .....	0800 838 0719
Anglesea Clinic .....	Mental Health Waikato Hospital .....	07 838 3752
<b>In an Emergency .....</b>	<b>111</b>	
Medical Helpline (Advice) .....	NZ Drug Foundation .....	0800 787 797
Mental Health Helpline .....	Police - Central Station .....	07 858 6200
Citizens Advice Bureau .....	Tenancy Service .....	0800 836 262
Dept of Work & Income .....	Victim Support Helpline .....	0800 8380719
Electricity Complaints .....	Crisis Team (CAT Team) .....	0800 50 50 50
Inland Revenue (IRD) .....	Depression Helpline .....	0800 111 757
Lifeline - Hamilton .....	Suicide Prevention Helpline .....	0508 828 865
	Health Line .....	0800 811 116

*The Trustees and staff would like to wish you all the very best for a Happy Christmas and New Year*





# NOTICE BOARD

## \*The Michael Ford / MS Waikato Golf Tournament\*

Our annual golf tournament will be taking place on the Friday 6th March 2015 at the Lochiel Golf Club.

We are seeking players, sponsors and volunteers for this, if you would like to participate in any way please call Janet on 07 834 4740 or email [janet@mswaikato.org.nz](mailto:janet@mswaikato.org.nz) for more information.

It's a great day out and all funds raised are used to assist with the provision of our services.

## SAINT JOHN'S CARING CALLER

Caring Caller is a service that St John provides for people who live alone or feel a bit lonely. Volunteers phone clients regularly to check that everything is ok.

If you wish to sign yourself up for this service and receive a regular call from a Caring Caller phone 0800 780 780.

## Subscriptions

Please note 2015 subscriptions are now due.

The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed.

Thank you for your support.

## Easy Rider - 'Wheelie Friendly' Travel Club

Waikato River Explorer - Thursday 11th December - \$65.00

Agrodome Show (Rotorua) - Thursday 29th January - \$70.00

Raglan Harbour Cruise - Thursday 12th March - \$65.00

For more information or to book a place contact Hilary on 07 829 8925 / 027 273 6767 or email [larry@easyrider.co.nz](mailto:larry@easyrider.co.nz)

## Christmas Closure

Please note our offices will be closed from

Wednesday 24th December and will re-open on Tuesday 20th January.

## Library Books

Please remember we maintain a library of books. With books to support MS, HD, ME/CFS/Fibromyalgia a list of titles is available on our website [www.mswaikato.org.nz](http://www.mswaikato.org.nz), under publications. Please contact us if you would like to borrow a book.

## Testing for Vitamin D Deficiency

If you wish to be tested for Vitamin D deficiency, testing is available from Pathlab for a fee of \$30.

## Vitamin D

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email [peterandcarole@xtra.co.nz](mailto:peterandcarole@xtra.co.nz)

## \*Donations and Bequests\*

Donations to MS Waikato can be made at anytime through our website [www.mswaikato.org.nz](http://www.mswaikato.org.nz), please click the link 'to make a donation' and it will take you to the Telecom Foundations give a little website, there are no fees with the site so we receive 100% of the donation you make. Alternatively a direct link to this site is through [www.givealittle.co.nz/org/MSWT](http://www.givealittle.co.nz/org/MSWT).

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

## Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

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The Lido • Anytime Fitness Tristram St • Lochiel Golf Club • Pak n Save Mill St • The Sutherland Self Help Trust





# MSWT EVENTS CALENDAR

## JANUARY 2015

SUN	MON	TUE	WED	THU	FRI	SAT
				1 <i>New Year's Day</i>	2	3
<b>** MS OFFICE CLOSED **</b>						
4	5	6	7 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	8	9	10
<b>** MS OFFICE CLOSED **</b>						
11	12 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	13	14 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	15	16	17
<b>** MS OFFICE CLOSED **</b>						
18	19 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	20 <b>MS OFFICE RE-OPENS</b>	21 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	22	23	24
25	26 <i>Auckland Anniversary</i>	27	28 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	29	30	31

## FEBRUARY 2015

SUN	MON	TUE	WED	THU	FRI	SAT
1	2 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton <b>MS Support Group</b> Te Awamutu 10am, Dusk Till Dawn	3	4 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5	6 <i>Waitangi Day</i>	7
8	9 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	10	11 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12 <b>ME/CFS Support Group</b> Methodist Church Bader St, Melville 10.30am	13	14
15	16 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	17	18 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19 <b>MS Support Group</b> Mometewa Matamata 10am	20	21
22	23 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	24 <b>ME (Chronic Fatigue)</b> Social Group Meeting Contact Tracey on 834 4745 for details Chartwell, 2pm <i>(to be confirmed)</i>	25 <b>MS Exercise Class</b> 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27	28

MS Waikato Trust, Life Unlimited Building, 20 Palmerston Street, PO Box 146, Hamilton 3240

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